

WORKING WITH A PARENT CARER FORUM



A QUICK GUIDE FOR THOSE WORKING IN THE **NHS** IN THE SOUTH EAST REGION



WHAT IS A PARENT CARER FORUM (PCF)

Legally

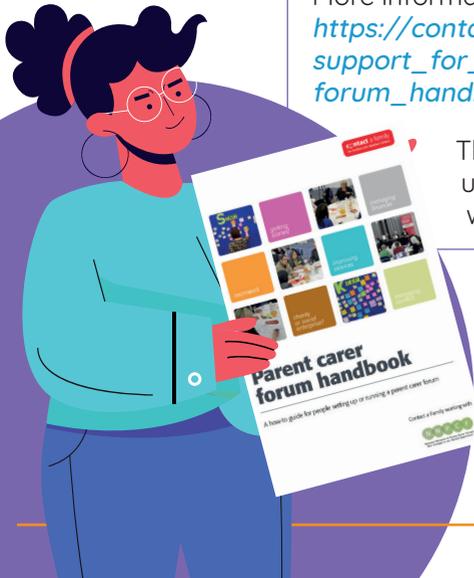
The Children and Families Act 2014 requires every local authority to recognise a Parent Carer Forum to represent the views of parent carers of children and young people with Special Educational Needs and Disabilities (SEND). Forums are also named in the OFSTED/CQC framework for local area inspections. However, it is important to remember that the Forums are geographically aligned to a local authority area, and these can and often do not correlate to current health oversight structures. In addition, Milton Keynes as a forum operates in the South East for parent carer purposes but in the East of England for NHS purposes. A list is provided in the Appendix matching each forum to its ICS area.

Structurally

Every forum will be different as there is no prescribed mode of operation. Currently in the South East NHS region, The 18 forums are a mixture of legal entities such as charitable bodies, constituted membership groups, and voluntary groups supported by an independent body. Even within each category, there is a variety of structures ranging from those with distinct trust bodies and paid staff to those whose activity is delivered almost entirely by volunteers.

More information on Forums can be found here https://contact.org.uk/wp-content/uploads/2021/03/support_for_parent_carer_forums_parent_carer_forum_handbook.pdf

This variety of structure is important to understand as it can determine the extent to which any forum can take up a new activity.



Financially

One of the main drivers for this variety is a lack of consistency on funding. The DfE provides the opportunity for each forum to bid for an annual grant of £17500 to cover their engagement activity. These grants are overseen by Contact, a charity with specific interest in family welfare, who are also funded to provide support to forums. In addition, some local authorities provide additional grants (which can be significant and may or may not be aligned to specific pieces of work) and health bodies do also provide funding in limited areas.



Regionally

In the south-east region, the forums come together to form a regional support network and pool funds for a part time administrative resource. Please do contact them if you are struggling to contact your local forum using the information in the Appendix or if you have a wider question on parent participation.

admin@southeastnnpf.org.uk

WHAT ARE THEY LOOKING TO ACHIEVE?



Better Outcomes

The main goal of parent carer forums is to improve outcomes for children and young people with SEND through improved provision in the local area to meet the spectrum of need that exists. They want to make the voice of parents and carers heard wherever and to whoever is making decisions that affect this goal. The aspiration of each forum is to work in coproduction with colleagues. By sharing the experience of families and their children and young people it is hoped that services can be tailored to match the very needs that left unaddressed will be barriers to future achievement.

Pragmatic Solutions

Acknowledging that the spectrum of need is considerable and that demand for health provision is increasing, forums seek to work with local health providers and commissioners to shape an offer that is practical and pragmatic. They want to deliver impactful change without the need for shouting and protesting; this occurs when they are treated as partners with a full contribution to make to all these discussions.

WHAT CAN THEY OFFER HELP WITH

Lived Experience

A forum's unique selling point is the lived experience not just of the reps who join meetings but of the members and the wider parent carer community whose views are fed into those reps. Forums help you hear what it is like to be a parent carer of a child or young person with SEND and to experience the services you offer.

Example: FACT Bucks have worked with commissioners and providers to establish termly dialogue meetings with service users aimed at feeding current lived experience into the system in a constructive way.

Real time data

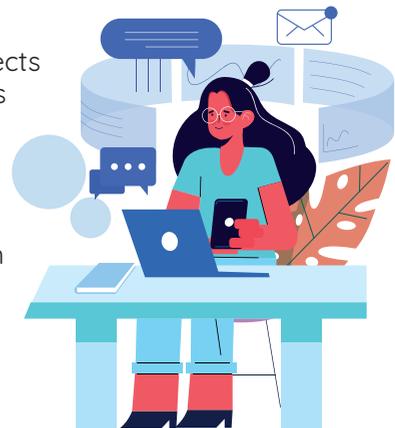
All forums will have ways to tap into the lived experience of parent carers. They may use direct member polls on individual subjects through social media; engage directly in conversations with parents in meetings – in person or online; use the network of local condition specific support groups; or periodic formal area wide surveys. However, they achieve it, they will have a pool of experience and real-time case studies to enhance your business planning and review exercises.

A different perspective

In all, they bring you a different perspective and help shape solutions to meet the needs in ways that you may never have considered. With the aim to provide solutions within resource and with the support of families.

Communication and planning

Forums can support your projects by channeling communications with families through various mediums. They can also advise on who best to lend a voice to inform planning and coproduction. Please approach them from the outset of a project; even if it might just be an idea. This is coproduction.



HOW BEST TO WORK WITH THEM

Listen

Forums are working to make the voice of parent carers heard, so firstly they want people to listen. They know that professionals do not have lots of spare time and so putting time aside to listen informally or in formal meetings, is valued. The listening is even more powerful when actions can be seen to arise from it.

Recognise

The governance structures around health are not as easily aligned to forum areas as noted at the beginning and therefore offering a place on governance boards is not always practical. However, if there are established routes within your organisation where the views of users are sought then this would be an opportunity to invite the forums. It is important is to recognise the forum represents a significant stakeholder group. A meeting with your forum will also help them to understand the health structures of your local area and scope what work could be jointly developed.

Understand

As noted at the start, forums differ in terms of funding and structure. As a result, the breadth of the activity they can engage in and the speed at which they can respond to requests will vary considerably. However, every forum will have a lead contact with whom the boundaries can be discussed. To aid your forum, consideration of funding is useful to ensure successful outcomes.

Co-produce

This is the 'gold standard' to which every forum aspires with all its working partners. It is a relationship, as well as a way of working, that starts conversations with questions and allows all parties to build the answer together - co-producing it. If the conversation starts with potential solutions or structures for comment and advice, then this is participation - which is welcome - but it will always fall short of that gold standard. A growing number of local authority areas have coproduction charters often endorsed by the relevant ICB.



COMMON BARRIERS



History

Parents are in their role over a long period and so forums often have a memory that extends beyond that of the key leadership in your organisation. As a result, they have historical experience collectively and individually that can create a barrier to engagement because promises have been made that have not been fulfilled. So, ask up front and help clear the air.

Local funding

As noted before, some forums enjoy productive relationships with local authority or health colleagues that has secured funding to enable the forum to establish a framework of operation that is robust. Most are not in this position and so the willingness of forums to take up the offer of more engagement may be tempered by an awareness that this will require even more voluntary time.

Anxiety among professionals

Hearing parent carers speaking of poor experiences of services, can be difficult for professionals to hear which can cause anxiety and upset, even when presented as case studies. Yet the value of the forum stems from those experiences as a springboard to improvement that meets need and changes outcomes.

Unwillingness to cede 'power'

As you consider working with forums and aspiring for coproduction, there will be elements of 'power' that cannot be shared – clinical judgement; employment rights; even funding decisions in complex organisations – but one element of power is always available to be shared – information – and yet an information imbalance is one of the most significant tools of power. As every school kid will tell you, the phrase 'I know something you don't' is very scary!

Respect

Forums consist of parent carers who will bring the experiences of their lives and those of their children and young people which you will be expecting. However, remember that parent carers are also people and before they were parent carers (and very often whilst they are parent carers) they are also still people, like you, working in the world, using skills that you might not have but which you could harness. Don't just see the parent carer – see the person behind the label!

PARENT CARER FORUMS IN THE **NHS** SOUTH EAST REGION

Buckinghamshire, Oxfordshire
& Berkshire West



Families & Carers Together in Bucks
admin@factbucks.org.uk
www.factbucks.org.uk



Oxfordshire Parent Carers Forum
info@oxpcf.org.uk
www.oxpcf.org.uk



SEND Voices Wokingham
info@sendvoiceswokingham.org.uk
www.sendvoiceswokingham.org.uk

Reading
Families'
Forum

Reading Families Forum
admin@factbucks.org.uk
www.factbucks.org.uk



West Berkshire Parent Carer Forum
TBA
TBA

Hampshire & Isle of Wight



**HAMPSHIRE
PARENT CARER
NETWORK**
enabling voices to be heard

Hampshire Parent Carer Network
Participation@hpcn.org.uk
www.hpcn.org.uk



Isle of Wight
Contactus@parentsvoice-iw.org.uk
website TBC



Portsmouth Parent Voice
ppv@hiveportsmouth.org.uk
www.portsmouthparentvoice.org



Southampton Parent Carer Forum
chair@sotonpcf.org.uk
www.sotonpcf.org.uk

NHS Surrey Heartlands



Family Voices Surrey
contact@familyvoicesurrey.org
www.familyvoicesurrey.org

NHS Sussex



Brighton & Hove Parent Carers Council
admin@paccbrighton.org.uk
www.paccbrighton.org.uk



East Sussex Parent Carer Forum
info@espcf.org.uk
www.espcf.org.uk



West Sussex Parent Carer Forum
office@wspcf.org.uk
www.wspcf.org.uk

Frimley



Bracknell Parent Carer Forum
Bracknell.pcf@gmail.com
www.bracknellpcf.com



Slough Special Voices
info@specialvoices.co.uk
www.specialvoices.co.uk



Send Voices RBWM
info@svrbwm.org.uk
www.svrbwm.org.uk

Kent & Medway



Kent Parents & carers Together
info@kentpact.org.uk
www.kentpact.org.uk



Medway Parents & Carers Forum
medwaypcf@googlemail.com
www.medwaypcf.org.uk

NHS Bedfordshire, Luton & Milton Keynes



Milton Keynes Parents & Carers Alliance
pacamk@gmail.com
www.pacamk.org

OTHER SOURCES OF INFO



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'

National Network of Parent Carer Forums
<https://www.nnpcf.org.uk>

contact *For families
with disabled children*

Contact (a Family)
<https://contact.org.uk>